

February 19, 2015

Public Health Committee
CT State House

Via: Hand Delivery by Julie Gortze, RN

Re: Establishment of Rare Disease Advisory Council

Dear Public Health Committee Members:

I am writing to support your committee establishing a Rare Disease Advisory Council in the State of Connecticut. I am a registered nurse working with individuals with rare diseases. It is perplexing to me why States, through their Departments of Health, have mandated newborn screening programs to identify rare disorders in newborns, and yet do not enforce insurance company coverage of medically necessary, and in many cases, lifesaving treatment for these disorders. Prevention of mental retardation and other catastrophic health complications is what initially the driving force behind mandating screening was. In the current age of medicine, we are able to identify so many diseases and disorders with ease, preventing complications and the need for costly placement for these individuals as families are no longer able to care for them. The difficult part is ability to access care after a diagnosis is made. There are obstacles to accessing care for many families. It would be beneficial for establishment of a Rare Disease Advisory Council to oversee, investigate and facilitate certain activities. These might include, but not be limited to, investigating barriers to appropriate care and therapies for disorders that are easily treated; overseeing insurance company criteria for coverage; and investigating exorbitant costs that are so financially burdensome patients go without treatment. Again, these are rare disorders, and therefore patients may never be heard. An Advisory Council may give these individuals a voice.

Thank you for your time and consideration.

Sincerely,

A handwritten signature in black ink that reads "Cheryl M. Clow, RN, CDE". The signature is written in a cursive, flowing style.

Cheryl Clow, RN, CDE
310 Route 66
Hudson, NY 12534